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BIA'S SMILE: AN HEALTH EDUCATION INSTRUMENT ON CLEFT LIP AND PALATE

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ABSTRACT

The human smile is a hegemonic factor to an aesthetically harmonious facial appearance and it is an elementary agent in a child's socialisation. Children manifesting sequels associated with cleft lip and palate (CLP) are likely to be targets of discriminatory attitudes; in the eyes of society, their aesthetically mutilated faces reach conspicuous stigmatizing visibility. Preventive interventions tackling social exclusion should be implemented, first and foremost, at schools; they should involve multidisciplinary teams and be aimed at enabling behavioural skills and social aptitudes among the peers of children with CLP, so as to allow deconstruction of prejudice associated with this condition. The health education tool now introduced is a children's book titled *Bia's Smile*. Its ludic-pedagogic goal is to build awareness and sensitivity in children aged 4 to 7 years old, as well as alert and inform education agents on the issue, with the ultimate object of the book being the eradication of social exclusion and bullying experienced by children with CLP. The children's book / learning textbook to mental health was designed so as to include a set of pictograms, inserted in the story's narrative. It should be noted that the available literature reveals a paucity of preventive programs on this issue, both at national and international level, which amplifies the pertinence of our ludic-pedagogic project.

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INTRODUCTION

Human smile is a hegemonic factor to an aesthetically harmonious facial appearance; is also constitutes an elementary agent in children's socialisation (Simões, 2015). Children manifesting sequels associated with cleft lip and palate (CLP) are likely to be targets of discriminatory attitudes; in the eyes of society, their aesthetically mutilated faces reach conspicuous stigmatizing visibility (Berkowitz, 2006; Simões, 2015).

Cleft lip and palate (CLP) refer to congenital craniofacial malformations, characterized by tissue discontinuity in the lip and upper alveolar arch and/or in soft and hard palates, that occur during embryonic development stage (Berkowitz, 2006; Conceição, 2013; Mondelli, Ventura & Feniman, 2013). That discontinuity compromises, at the anatomo-physiological level, the development of the oropharyngeal cavity, carrying implications in functions such as nutrition, hearing, and language; it also generates sequels as to the child's

socialisation and affective-emotional states (Berkowitz, 2006; Martins & Cardoso, 2015; Migueis, 2015; Oliveira, Resende, Ibiapina & Godinho, 2013).

One classification widely used by health professionals is that proposed by Spina (1973), which reference point is the incisive foramen – an opening that, following the anatomic topography of the face, corresponds to the anterior third of the median line of the palate (Conceição, 2013; Migueis, 2015; Spina, 1973) – specifically, the juncture of primary palate (upper lip and alveolar arch) with secondary palate (soft and hard palate), originating three different types of split, or cleft: *pre-incisive foramen cleft*, *post-incisive foramen cleft* and *trans-incisive foramen cleft* (Conceição, 2013; Migueis, 2015; Spina, 1973). Pre-incisive foramen cleft, also called *cleft lip*, involves the upper lip and the alveolar arch up to the incisive foramen, keeping both palates intact. That condition allows for a more efficient suction pattern, and children so affected do not exhibit severe eating complications; it does not, however, preclude

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difficulties in adjusting both upper and lower lips around the mother's nipple and/or bottle's teat, resulting in unavoidable milk spillage (Berkowitz, 2006; Branco & Cardoso, 2013; Conceição, 2013; Migueis, 2015; Spina, 1973). Post-incisive foramen cleft, or *palate cleft*, involves both soft and hard palates, and is characterized by absence of boundaries between the oral and nasal cavities (Berkowitz, 2006; Branco & Cardoso, 2013; Conceição, 2013; Migueis, 2015; Spina, 1973). In that condition, children evidence difficulties in keeping a successful suction pattern, often resulting in nasal regurgitation. Furthermore, the tongue does not have adequate support to efficiently swallow the bolus (Berkowitz, 2006; Cichero & Murdoch, 2006; Rajion, Al-Khatib, Netherway, Townsend, Anderson, McLean & Samsudin, 2012). Trans-incisive foramen cleft, also known as *cleft lip and palate*, involves the two previously described conditions simultaneously, i.e., it damages primary and secondary palates, from the lip to the uvula, compromising the entire upper territory of the oral cavity. Difficulties experienced by a child affected by cleft and lip palate are, unsurprisingly, more accented (Conceição, 2013; Migueis, 2015; Spina, 1973).

Normal development of speech requires not only language and oral-motor coordination skills, but also auditory and velopharyngeal aptitude, the engagement of the child's own psychosocial abilities, and a regular configuration of the vocal tract – a configuration that will shape the sounds of speech and render their amplification possible through the resonance cavities (Berkowitz, 2006; Yang, Fan, Tian, Liu, Gan, Chen & Yin, 2014). Now, in children with CLP, the morphologic configuration of the oral cavity frequently leads to velopharyngeal insufficiency, a complication that, besides inducing changes in phonation, eating difficulties and nasal regurgitation, also results in an increase of nasal resonance (hypernasality) which, in turn, makes it more likely for the condition to be socially conspicuous, consequently occasioning others to adopt disparaging attitudes toward the child (Berkowitz, 2006; Girelli, Selaimen de Costa, Collares & Dornelles, 2016; Piotet, Beguin, Broome, Iglesias, Olivier, Leuchter, Zbinden, Hohlfeld, Roessingh, Schweizer & Pasche, 2015; Yang, Fan, Tian, Liu, Gan, Chen & Yin, 2014).

Auditory-perceptive alterations as to voice quality, along with imprecise verbal articulation, can also be found in children with CPL, given that, in an attempt to mimic as close as they can what they perceive to be the normal speech sound, children with CLP adopt incorrect compensatory postures (Berkowitz, 2006; Conceição, 2013; Girelli, Selaimen de Costa, Collares & Dornelles, 2016; Martins & Cardoso, 2015). CLP makes speech intelligibility more difficult, leading to 'fractures' in the child's interpersonal relation with their peers (Dias, Duque & Silva, 2002). CLP also gives rise to other complications that hinder socialisation, namely, hearing complications and resulting difficulties in the normal process of language acquisition and development (El Ezzi, Herzog, Broome, Trichet-Zbinden, Hohlfeld, Cherpillod & Roessingh, 2015; Silva, Nascimento & Santos, 2004; Stock & Feragen, 2016).

The first intra- and inter-social relations any child forges are with their parental figures, most especially with their mother. The quality of that mother-infant relation emerges as the basic foundation for the child's language development and psychosocial relation with the *Other* (Brocchi & Leme, 2013;

Stock & Feragen, 2016). That foundation can become emotionally compromised in children with CLP. During gestation, parents develop expectations regarding the baby, hoping that their 'perfect baby' will be able to overcome all 'narcissistic wounds' they themselves experienced (Ferrari, Picinini & Lopes, 2006; Vanz & Ribeiro, 2011). Some authors argue that, on an unconscious level, a baby is a psychological investment on the part of their parents, whose narcissistic desires lead to the psychological presence of a psychic configuration of three babies: (i) the *phantasmal baby*; (ii) the *imaginary baby*; and (iii) the *real baby* (Gianlupi, 2003; Silva, 2012; Vanz & Ribeiro, 2011). CLP constitutes a visually perceptive imperfection that parents cannot fail to acknowledge at the very moment of the baby's birth; parents are confronted with a mix of emotions, triggering feelings of inability to generate healthy and perfect offspring. The situation is compounded by the fact that that imperfection is patent in the baby's face, for in the eyes of society the child's aesthetically mutilated face reaches a conspicuous and stigmatizing visibility (Gassling, Christoph, Wahle, Koos, Wiltfang, Gerber, Siniatchkin, 2014; Nidey, Moreno Uribe, Marazita & Wehby, 2015; Thamilselvan, Kumar, Murthy, Sharma & Kumar, 2015; Vanz & Ribeiro, 2011).

One's face works as one's social 'calling card', having a significant impact on first impressions and in social interactions, and the dental-facial area is that which most prominently contributes to the aesthetic overall look of one's face. Smile and dental appearance are crucial factors to a harmonious facial look, the smile being a particularly fundamental agent in the child's socialisation success. A child with CLP may become a target for discriminatory and prejudiced attitudes, in that the stigma associated with this condition achieves higher visibility and noticeability in the 'eyes' of society (Albuquerque, 2014; Berkowitz, 2006; Dias, Duque & Silva, 2002; Gassling, Christoph, Wahle, Koos, Wiltfang, Gerber, Siniatchkin, 2014; Simões, 2015).

Stigmatisation of children with CLP is clearly noticeable during their school years. There is no consensus as to whether such stigmatisation shows a gender bias: some authors state it to be more pronounced within females (Simões, 2015), whereas others mention its prevalence within males, accompanied by bullying behaviours (Lorot-Marchand, Guerreschi, Pellerin, Martinot, Gbaguidi, Neiva, Devauchelle, Frochisse, Poli-Merol & Francois-Fiquet, 2015; Plas, Kosciak, Conrad, Moser & Nopoulos, 2013; Shapiro, Waljee, Ranganathan, Buchman & Warschausky, 2015; Simões, 2015). Whichever the case, children with CLP, by virtue of the personality traits they manifest (shyness, lack of self-confidence, low self-esteem) and the high social anxiety they seem to experience, end up having a rather small and confined circle of friends. In some cases, they also show lack of motivation to participate in social contacts or activities – a conduct that could perhaps stem from a poorly stimulating relation between child and parents/caregivers, who are the first and primary agents in the child's psychosocial development (Brocchi & Leme, 2013; Plas, Kosciak, Conrad, Moser & Nopoulos, 2013; Stock & Feragen, 2016).

Interventions aimed at tackling both stigmatisation and social exclusion should be carried out, to begin with, in schools, with

recourse to a multidisciplinary team, with a view to develop social and behavioural skills and aptitudes and they should address groups and focus on assailant aggressors and victims (Shetgiri, 2013), given that the knowledge (information) factor is a determining variable that allows to mitigate the crystallisation of prejudices towards children with CLP (Dias, Ferrer, Rigla, 1997).

School is a relevant social arena when it comes to Mental Health Promotion and Education, for it provides the context where a difference can be made via implementation of preventive and pedagogic actions aimed at humanising and effecting social inclusion of children with CLP. The joint intervention of health professionals (dentists, speech therapists and/or psychologists) in school context, alongside teachers, educators and school staff in general, is a health promotion and education strategy which ultimate goal is to explain to children what CLP is (Dias, Ferrer, Rigla, 1997; Silva, Locks, Carcereri & Silva, 2013). Recent studies show positive results at the level of interdisciplinary interventions, showing that they contribute to successfully referring children with CLP to speech therapy and to psychological counselling (Lorot-Marchand, Guerreschi, Pellerin, Martinot, Gbaguidi, Neiva, Devauchelle, Frochisse, Poli-Merol & Francois-Fiquet, 2015; Silva, Locks, Carcereri & Silva, 2013).

The current paper introduces a Mental Health Education Instrument that, in the context of joint interventions carried out in schools, enables both speech therapists and psychologists to teach children about CLP in a playful and interactive manner. It is important to reach out to school-aged children; not just because it is in this stage that we see higher levels of stigmatisation, but also because it is during this period of development that a higher ability/fluidity for learning, behavioural modelling and for the resulting cognitive shifting exists.

The instrument we have developed is a children's book aimed at making children aged between 4 and seven years old aware of, and sensitive to, issues pertaining to CLP. Specifically, it is intended to let children know what does the CLP pathology consist in, and how to recognise stereotypes associated with / triggered by children with CLP; in so doing, the book aims at helping to combat social exclusion.

METHODOLOGY/ METHODS

The proposed Mental Health Education Instrument was developed with a view to instruct and alert to the issue of social-affective inclusion/exclusion of stigmatised children with CLP. This health education tool was tailored to be used by children of both sexes, aged between four and seven years old – the period of development where a greater psychological plasticity exists to assimilate new contents/concepts and where a greater ability is manifest to make use of symbolic play (Palangana, 2015).

In that stage of cognitive development (the period that Piaget called pre-operational), children begin to discern differences between fantasy and reality, realising that, in most cases, ludic-pedagogic tools can be interpreted as living objects in real situations. Pre-operational children also show the ability to memorise and reproduce stories, to understand spatial and temporal concepts associated with themselves, a moral

consciousness of right and wrong, as well as a more acute sensitivity to the other's needs and feelings (Palangana, 2015). We have thus set to develop a book that reflects the entire problematic associated with CLP, including age-appropriate clarification on that pathology and acknowledgment of the feelings that are triggered in children and family members/caregivers when they lack knowledge of what that pathology is and entails. The goal is to name the experience intra-psychologically, thus learning to cope with the emotions associated with the "aesthetic conflict" of the face that, naturally, unearths movements associated with social exclusion. The current state of lack of information on CLP among the population in general, and among the younger sectors of society in particular, makes us believe that only by bridging that information gap will we be able to see a change in attitudes – the empirical evidence of acceptance and valorisation of the *Other*. We are thus firmly convinced that health education instruments on CLP should be early implemented, i.e., in the pre-school stage (Dias, Ferrer & Rigla, 1997).

The children's book we have developed features a series of pictograms, illustrative of the story that is being told and inserted alongside the narrative, as seen in Figure 1 (where we have the pictograms depicting the main character: "Bia" and her "smile"). Images help calling children's attention to the universe of children's literature, in that they provide a visual narrative alongside a verbal narrative, helping children to develop reading abilities in a pedagogic way and with free access to the story. When illustrations are integrated in the verbal content, it contributes to deepen reading perception in the child, stimulating their imagination and observation, thus fostering the child's overall development (Mello, 2013; Ribeiro, 2011).

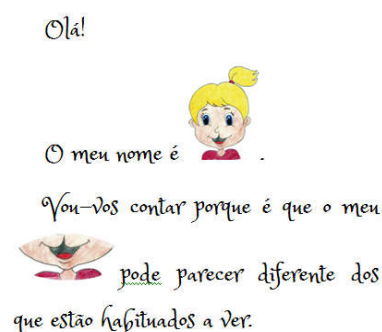


Figure 1

'Hi! My name is [Bia].

I'm going to tell you why my [smile] may seem different from the smiles that you're used to see.'

Illustrations have thus the ability of enliven a character, endowing it with personality, age and other distinctive elements, as we can see in Figure 2, where the main character of the story – Bia – is portrayed. We learn that Bia is a seven year old girl that was born with CLP, who shows difficulties in speech articulation and voice quality that cause easy and discriminatory laughter among her classmates. The character aims at representing every child with CLP that endures social exclusion due to their peers' lack of knowledge about their pathology, as well as due to their aesthetical-facial aspect (Carelli & Aquino, 2013). The use of pictograms when dealing

with health-relates issues allows one to capture basic elements that express the crucial information one intends to get across; enlisting pictorial symbolism as an asset is an excellent means of conveying an idea, and a privileged vehicle of communication (Dias, Oliveira & Bastos, 2015).



Figure 2

Children's stories promote the development of a set of psychomotor abilities; they stimulate the child's imagination, the development of cognitive aptitudes, they boost language, and furthermore improve and intensify reading and writing acquisition processes (Souza & Bernardino, 2011). By virtue of their ludic component, children's literature has the power to expose children to a varied range of themes, thus influencing the formation of critical and reflexive thinking, reaching values such as humane conduct and promoting awareness of issues like CLP (Coletto, 2010; Ribeiro, Castro & Filho, 2014). When reading a book, a child brings into their psychological world not just the story, but also whichever images are presented to them over the pages of the book they are reading; that allows the child to interpret the book's message as integral part of their psychological universe and, particularly, to understand the story via visual reading (Santos, 2008).

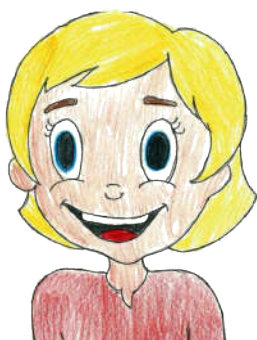


Figure 3

For the children's book we are currently presenting, we have designed 24 illustrations, comprising 42 pictograms alongside the text and 6 pictograms that depict the story's narrative.

Figure 3 shows Bia's mother, a salient character throughout the story, in that it is she who explains to Bia the whys and wherefores of her smile being different from that of other children. In the course of the narrative, Bia's mother will also show her emotional holding when faced with a situation where Bia's classmates bully her, for she is known at her school by her nickname – 'Mouths' (represented in Figure 4).

M – O – U – T – H – S – Y

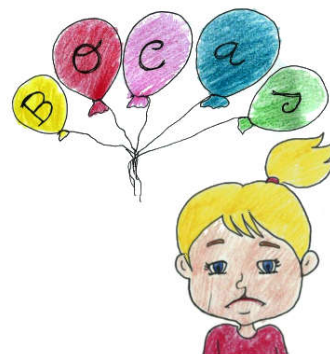


Figure 4

Children with CLP evidence negative reactions when confronted with social exclusion attitudes manifested by their peers. Those reactions often take the form of social withdrawal and low self-esteem, brought about by self-consciousness regarding their physical appearance; such responses, tend to 'evolve' to feelings of non-belonging the peer group (Lorot-Marchand, Guerreschi, Pellerin, Martinot, Gbaguidi, Neiva, Devauchelle, Frochisse, Poli-Merol & Francois-Fiquet, 2015; Oliveira, Yasunaga, Sebastian & Nascimento, 2010; Dias, Lynce de Faria & Ibrahim, 2013; Plas, Kosciak, Conrad, Moser & Nopoulos, 2013).

Since their early years and throughout their life, children with CLP are chosen as preferential targets of verbal abuse by their peers, an abuse that ranges from harassment, to name-calling, to threats, teasing and/or psychological intimidation – the harder-to-detect type of bullying, when compared to signs of physical aggression (Albuquerque, 2014; Dias, Lynce de Faria & Ibrahim, 2013; Lorot-Marchand, Guerreschi, Pellerin, Martinot, Gbaguidi, Neiva, Devauchelle, Frochisse, Poli-Merol & Francois-Fiquet, 2015; Shetgiri, 2013; Simões, 2015). Victims of those forms of abuse sometimes present psychosomatic ailments such as headaches or stomachaches (Figure 5), particularly in the morning, when they are about to leave for school (Berkowitz, 2006; Brocchi & Leme, 2013; Dias, 1994; Dias, Lynce de Faria & Ibrahim, 2013; Plas, Kosciak, Conrad, Moser & Nopoulos, 2013; Shetgiri, 2013; Simões, 2015; Stock & Feragen, 2016).

No final do dia quando a minha



chegou para me vir buscar,



a chorar e disse-lhe:

- "Mãe não quero vir mais à



!

Figure 5

'At the end of the day, when my [mother] arrived to pick me up from school, [I] was crying and said to her:
- Mummy, I don't want to come to [school] again!'

Still in Figure 5, Bia's mother explains to her that she is a special little girl, and that it will not be due to her facial aesthetics that she will be rejected by her peers. In the story, that symbolic equation is represented – allegorically and metaphorically – by a flower (Figure 6) that does not cease to be beautiful just because it lacks a petal (Dias, Lynce de Faria & Ibrahim, 2013).



Figure 6

'- Do you see this [flower] here? It is growing, just like you are. It is missing a [petal], but she does not stop being beautiful. It is the same with you.'

Pictograms were conceived employing the most commonly used technique of reflection of children's latent and psychodynamic content – drawing (Cariola, 2006). As a means of representation of thoughts and feelings, drawing is the most primitive form of human communication (Costa & Arriaga, 2015; Fávero & Salim, 1995; Mello, 2013; Menezes, Moré & Cruz, 2008) and, as a form of cognitive and emotional expression, by virtue of it being a basic and universal language, it is a projective tool which symbolic value allows the child to express how they experience situations and the meaning they ascribe to them (Dias & Simões, 2016; Grubits, 2003; Mello, 2013; Menezes, Moré & Cruz, 2008; Vygotsky, 2000).

Children's drawings also allow the child to organize information and process experiences they have lived and thought through, helping them to develop a personal and unique style of representing the world (Mello, 2013; Menezes, Moré & Cruz, 2008; Moreira, 2002).

Through drawing illustrations, growing children are able to obtain information and knowledge about the world around them. Because they also are excellent resources in helping parents and educators when they wish to explain specific issues, as is the case with CLP (Dias, Lynce de Faria & Ibrahim, 2013; Mello, 2013; Ribeiro, 2011), making use of drawings is a strategy that can be employed in areas such as education, psychology and speech therapy (Costa & Arriaga, 2015). Pictorial illustrations allow children to build a pre-conception – via projective identification, personal identity, awareness of cultural heritage and eradication of social stereotypes (Moreira, 2002; Mello, 2013; Ribeiro, 2011). In the context of a book, children's illustrations should assist in and

complement the telling of the story, offering to the child the possibility of exercising their imagination and create a psychological space for action and mental representation (Ribeiro, 2011). The use of drawings makes it possible to improve children's attention and motivation; it simulates real-life situations through the construction of settings; it contributes to reading comprehension and writing acquisition pertaining to the construction of concepts and to the child's relation with those concepts; it synthesizes information and helps memorisation of facts and events (Dias, Lynce de Faria & Ibrahim, 2013; Dieguez, 1978; García, 2008).



Figure 7

One other relevant character in the book, due to her important role in Bia's therapeutic rehabilitation, is the speech therapist (Figure 7). Working in close collaboration with the psychologist, the speech therapist helped Bia improve certain functions: eating, deglutition, phonation and verbal articulation. The book also contains an index (see Figure 8) that allows children (with the aid of parents and teachers) to better understand the symbolic meaning of each pictogram that illustrates and complements the story.



Figure 8

Friends – Toys
Sad – Words

Play – Sounds
Speak – Tongue

Despite mass media emancipation, our society continues to esteem books as indispensable vehicles of communication and knowledge carriers. Considering that education agents should promote the development of strategies to deal with situations of intimidating/prosecutorial character, we believe *Bia's Smile* to be a relevant and pertinent tool for mental health education.

CONCLUSION

The mental health education instrument described in the current paper is a children's book titled *Bia's Smile*. This book has the ludic-pedagogic goal of making children aged four to seven years old (and, indirectly, parents and educators) aware of and sensitive to issues concerning CLP, including biophycosocial implications that children with CLP are vulnerable to, with a view to eradicate social exclusion and bullying behaviours associated with CLP.

The book was conceived based on a set of pictograms that co-illustrate the verbal narrative of the story itself. The images it contains – drawings – attract children's attention to the universe of literature, also facilitating the acquisition of social coping strategies. The instrument developed has a ludic-pedagogic and intervention-oriented character, usable by health professionals, children, educators and related social support structures; mental health promotion and education actions that tackle CLP can be promoted not only among the general population, as also, and most significantly, in schools – an investment in the younger sectors of society.

The reviewed literature shows that there are virtually no education initiatives along the lines of the one we propose in Portugal, which makes the ludic-pedagogic project we now present all the more pertinent. Generally speaking, and as shown by several empirical studies, the benefits and effectiveness of disseminating information aimed at changing discriminatory attitudes and social exclusion are rather clear. *Bia's Smile*, a product that works both as children's book and Mental Health Education Textbook, intends to mitigate the paucity of scientific instruments available, providing a tool for ludic-pedagogic-relational and socio-educational intervention.

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